

Evaluation of mammographic surveillance services in women under 50 with a family history of breast cancer. (FH01 project)

FH01 Collaborators' Meeting, 8th June 2004, UCL

Meeting Notes

Dr Mackay opened the meeting by welcoming everybody to the meeting and outlining the agenda for the afternoon

Stephen Duffy gave a presentation outlining the funding details and the additional funding and extension received. He gave some details about some related projects such as the Age 30-39 study and the Hodgkins Lymphoma study.

The eligibility criteria were reinforced and centres asked to check carefully that women fitted the criteria before being entered into the study. It was emphasised that centres were not to change their local protocols but just ensure the ladies being entered into the study fulfil the criteria. It was stated that relatives ages were not to be averaged in order to fulfil the entry criteria.

Some of the problems delaying centres recruiting were highlighted such as LREC and R&D forms.

Sue Thomas circulated a spreadsheet with the latest recruitment figures and details of the sites who were ready to start recruiting and those awaiting LREC and R&D approval. Sue emphasised that there was a need to have copies of the consent forms for each lady being recruited. This was how Sue accrued the recruitment figures. It was sufficient to send the forms at the end of each month. Recruitment figures were reported to the NCRN Trials portfolio and the HTA each month.

Sue also informed the meeting that a new consent form was to be used following approval from MREC. Copies were available but would also be circulated to recruiting centres shortly. There was no need to inform LREC about the change of consent form

Discussion. Followed on the subject of start up and recruitment problems from individual centres.

Several centres highlighted the lack of local support. This was often for hands on activities like pulling notes or trawling through notes or databases to identify potential recruits. It was stated by several centres that their computer systems were inadequate and could not be interrogated either easily or at all to identify recruits.

LREC process appeared to be fairly straight forward in the majority of cases. Trust

There was some discussion re the Standards of mammography as indicated in the Study protocol. There was concern that some centres recruiting that held family history clinics as a part of the symptomatic service would not fulfil all the study standards.

The shortage of Radiographers was highlighted as a problem along with local policies of frequency of mammograms for family history women. It was felt that the release of the NICE guidelines would help solve the problems of frequency of mammograms. The possibility of transporting mammograms to other centres to be read was discussed.

Eila Watson, gave the meeting some background information about the PIMMS study and some very interesting responses from some of their recruits.

After Tea a general discussion took place as to what centres felt was necessary to improve the pace of start up and recruitment?

In some centres financial support to help the initial review of notes to establish a woman's eligibility for the study would be very helpful.

A letter of introduction to be sent on behalf of centres to potential recruits explaining the study was thought to be helpful

The NCRN accrual figures, currently do not include screening trials. It was agreed by the meeting that if the study's recruits counted towards the NCRN accrual figures, this would help centres include FH01 in their portfolio.

A lot of discussion took place as to how the release of the NICE Guidelines would influence the Study. It was suggested that a press release would be helpful for centres to use. Discussion took place as to whether NHS Direct would be given appropriate information and other websites such as Cancer Bacup and CRUK

The main points for action from the meeting are tabled below:-

	Action	Result
NCRN Accrual Figures	Management group to write to Peter Selby/Maxine Stead	
Mammography Standards	Management group to compile audit protocol	
Short Term money to hasten start up	Centres to contact Stephen Duffy with their needs	
Letter of introduction	Sue Thomas to write letter/data collection form	
Press release for NICE guidelines	ST to coordinate for BTW, SWD for CR-UK	
Updated consent form	To be circulated	